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## Palliative Players: Project Development and Initial Implementation

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# PALLIATIVE PLAYERS

Project Development and Initial Implementation

The Palliative Players project is an innovative effort to train and use hospice volunteers as simulated patients in workshops teaching serious illness conversation skills to clinicians and other healthcare workers.

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## Summary

The Palliative Players are screened and trained hospice volunteers who provide a low-cost, sustainable, role-playing resource for use teaching communication skills to healthcare workers who discuss serious illness with patients and their families. The Palliative Players project was conceived and developed in early 2017 by Dr. Lauren Michalakes, Medical Director of Palliative Care at Coastal Healthcare Alliance (CHA); Sarah Dwelley, RN; Flic Shooter, Director of Hospice Volunteers of Waldo County (HVOWC); and Eliza Eager, Project Coordinator; to provide believable, emotive simulated patients (SPs) for role-play in workshops teaching healthcare workers communication tools and skills for use in conversations with patients and families facing serious illness.

Nationally, there are excellent tools and systems for teaching serious illness conversation skills to physicians and nurse practitioners, including VitalTalk (VitalTalk, 2017), and the Serious Illness Conversation Program (SICP) (Ariadne Labs, 2017). As designed, however, neither of these tools entirely fits all the needs and system constraints of rural Maine; nor were they designed for use teaching goals of care conversation skills to the nurses, social workers and other healthcare workers who can and do have these conversations with patients. The Palliative Players project adapts, expands, and combines existing tools, training hospice volunteers to be dynamic teaching resource for role-play of serious illness conversations.

This capstone paper describes the development of the Palliative Players project, including training and management details and lessons learned in project implementation to date. Training materials used and developed are found in the Appendices.

## Background

According to Dr. Anthony Back, approximately two million Americans receive “bad medical news” and die every year (Back, 2016). Medical training increasingly includes “communication” in the competencies set, however many doctors are undertrained and uncomfortable with having conversations about serious illness with their patients (Orgel, McCarter, & Jacobs, 2010). Demand for the communication skills that are a centerpiece of palliative care is building. Palliative care specialists are increasingly called on to discuss goals of care with patients and families (Arnold, Back, & Tulsky, 2016), and to teach these skills to colleagues in other specializations (Carlson, Lim, & Meier, 2011; Ceronsky, Shearer, Weng, Hopkins, & McKinley, 2013; Jacobsen, Whitlock, Lee, Lindvall, & Jackson, 2015).

Many clinicians are uncomfortable with prognostication *and* with discussing prognosis with patients and families (Jacobsen et al., 2015; Mack & Smith, 2012). However, many patients want and need this information (Ray, Wright, & Zhang, 2008).

Effective clinical communication skills are not innate (Drazen, Shields, & Loscalzo, 2014); and communication of medical news is stressful for providers (Back, Jackson, Steinhauser, & Kamal, 2016; Cohen et al., 2003). It has been reported that communication training that includes role-play with a simulated patient can effectively improve healthcare provider communication skill (Schlegel, Woermann, Shaha, Rethans, & Vleuten, 2012; Szmilowicz et al., 2012), that even a short workshop intervention can improve communication skill (Alexander, Keitz, Sloane, & Tulsky, 2006; Williams, Fisicaro, Veloski, & Berg, 2011), and that these improvements can persist over time (Wayne et al., 2012).

There is interest nationwide in tools to train physicians and other providers at all levels of experience to have more effective conversations about serious illness (Drazen et al., 2014). Led by large urban academic medical centers, campaigns are underway to build clinician skill and confidence in having difficult conversations – notably VitalTalk (VitalTalk, 2017) and the Serious Illness Conversation Program (SICP) (Ariadne Labs, 2017). “Champions” trained to share this work are spreading across the country, though resources and funding for these trainings is scarcer in rural areas.

Some larger health systems devote resources to train and employ simulated patients (SPs), actors or otherwise extensively trained individuals, to assume patient/case personae, for use in role-playing as a component of their educational programming (Back et al., 2007). Smaller healthcare organizations, including some in Maine, seek communication trainings led by palliative care experts that include opportunities for all learners to participate in role-playing. Community size and budget constraints can make professional actors trained to serve as SPs unavailable for such workshops, reflecting the findings in the literature that the three barriers to the use of SPs in communication role-play are: cost, human relations issues, and quality control (Hart & Chilcote, 2016).

# Methods

## 1. Review of the Literature

A substantial review of the literature was conducted. SP training tools and methods, as well as acting and role development tools and methods, were collected and synthesized. The web publications of two nationally acclaimed programs teaching goals of care conversations, VitalTalk and SICP, were extensively reviewed.

Recommendations found in the literature informed the development of this project:

- Careful attention to recruitment and selection criteria for role-play actors can help ensure that they will prepare, attend, and suit the role they have been chosen to play. (Cleland, Abe, & Rethans, 2009; Pascucci, Weinstock, O'Connor, Fancy, & Meyer, 2014).
- SP and actor trainings should include:
  - a review of the case each actor is assigned to portray, with opportunities to ask questions and to develop the character, i.e. practice role-play (Pascucci et al., 2014)
  - an opportunity to watch and practice role-play, in a group, with Instructor feedback (Berkhof, van Rijssen, Schellart, Anema, & van der Beek, 2011)
  - a review of the skills to be taught to learners in the workshops, and the development of the capacity to adjust the level of challenge the SP presents to the learner in response to learner skill (Bays et al., 2014).
  - specific key elements of SP role-play including a sustained, emotional silence (Back et al., 2007)
  - physical components of role-play (Hamilton et al., 2014)
  - guidelines for maintaining a safe learning environment for learners with various learning styles, while pursuing a variety of didactic agendas, and with limited time (Jackson & Back, 2011)
  - guidance on conversational dominance (de la Croix & Skelton, 2013).

And, a validated instrument for assessment of SP role-play performance (Perera, Perera, Abdullah, & Lee, 2009) was identified for use in this project.

## 2. VitalTalk Training

Participation in a one-day VitalTalk training in February, 2017 significantly informed the development of the Palliative Players (Arnold, Back, & Tulsy, 2017). Elements of VitalTalk training were incorporated in the training of the Palliative Players and as a part of workshops featuring role-play with the Palliative Players.

The VitalTalk training featured communication skills for physicians and other clinicians, broken down into component techniques and steps, using a carefully choreographed combination of didactics, and group role-play sessions. A day-long intensive workshop, VitalTalk training included two small group sessions (approximately 10 participants), in which all learners discussed the skills taught in didactic sessions and took turns in the “hot seat,” role-playing with a professional actor, observing each other closely, and offering feedback to fellow learners.

VitalTalk hires actors to serve as SPs in extensive role-play with learners, and invests at least a full day training actors prior to VitalTalk workshops. Actor’s personas/cases for role-play are finely detailed. And, actors are coached to respond to learners with emotion, sometimes forcefully, to give each learner the opportunity to work through simulated patients’ emotional reactions to the delivery of grave medical news (Michalakes, 2017).

The VitalTalk training provided a diverse set of tools for connecting with and responding to patients of all emotional styles during difficult conversations. VitalTalk teaches mnemonics to help clinicians recall tools to navigate prognosis and goals of care conversations. One of these sets of communication tools was used in training the Palliative Players: **NURSE**. These skills include: **N**aming the patient’s emotion, **U**nderstanding what the patient thinks and knows, **R**especting the patient’s effort and care, **S**upporting the patient by committing to their journey, and **E**xploring in more detail the patient’s thoughts (Arnold et al., 2017). (See Appendix L: VitalTalk Key Element Guide for Palliative Players.)



The VitalTalk intensive communication skill coaching, including the use of “actors” to improvise as patients in conversations about prognosis and goals of care, was adapted for use in workshops at Coastal Healthcare Alliance (CHA) hospitals featuring local hospice volunteers rather than actors – the Palliative Players.

### **3. Serious Illness Care Guide**

SICP materials were developed by Ariadne Labs and the Dana-Farber Cancer Institute in Boston. These tools have achieved significant reach, notably due to the efforts of bestselling author and surgeon Dr. Atul Gawande. Like VitalTalk tools, the SICP Guide was designed as a tool for physicians and other clinicians, breaking serious illness conversations into a series of steps (Ariadne Labs & Dana-Farber Cancer Institute, 2015) mimicking the teaching of other clinical skills. The Serious Illness Care Guide includes patient-tested language and a conversation outline in the form of semi-scripted lines which is used in role-play with fellow learners in SICP workshops.

As designed by Ariadne Labs, the component parts of the Serious Illness Conversation Guide may be used individually, or the complete Guide may be used as a checklist to help providers keep difficult conversations on track. The patient-tested language of the Guide gives structure to difficult conversations.

The Palliative Players were trained using SICP case histories and scripts. SICP materials were reformatted and adapted for ease of use by the Palliative Players, including the “Conversation Key Elements Guide” (see Appendix K) which was developed for the Palliative Players as a part of this capstone project.

#### **4. Participation in SICIP training at Coastal Healthcare Alliance Hospitals**

Communication workshops using the SICIP Guide, videos, other materials, and role-play were offered at Coastal Healthcare Alliance (CHA) hospitals beginning in March of 2017. Observation of and participation in the first of these workshops, which included role-play with fellow learners among the nursing and social work staff in attendance, informed the development of the Palliative Players concept and training materials.

#### **5. Development and Adaptation of Tools**

Regular meetings and communication were required to develop plans and materials for this project. The training team included: Dr. Lauren Michalakes and Sarah Dwelley RN of CHA, and Flic Shooter and Eliza Eager of Hospice Volunteers of Waldo County (HVOWC).

Training team members communicated in person or by telephone bi-weekly from February to April 2017. Workshops that adapted and expanded SICIP training to incorporate aspects of the VitalTalk method were developed through this iterative collaboration (these adapted workshops are referred to as “CHASICIP workshops” below).

#### **6. Feedback Collection**

The Project Coordinator held debrief conversations in person or by telephone with each member of the training team within 48 hours after each Palliative Player training session and CHASICIP workshop. A feedback sheet was developed and used to capture participant input following each training session (see Appendix M).

This feedback informed planning for each subsequent Palliative Player training session and CHASICIP workshop, revealing Palliative Player needs, competences, and level of confidence as SPs, through the training process and workshops.

## **7. Piloting**

Three clinical workers (nurses and social workers) who had completed the SICIP workshop in March 2017 were invited to practice role-play with the Palliative Players to pilot this project before use in CHASICIP workshops. Written feedback from these clinical staff members as well as from the Palliative Players was collected following this session. Observation of role-play at this pilot session, by Dr. Michalakes (the Instructor) and the Project Coordinator, confirmed that the Palliative Players were ready for debut in CHASICIP workshops.

## Initial Implementation

The Palliative Players were managed by the HVOWC Project Coordinator. The Project Coordinator organized Palliative Players trainings and workshops; and solicited, reviewed, and responded to Palliative Player feedback and concerns.

The Palliative Players were trained collaboratively by all members of the training team. The Project Coordinator prepared materials and agendas for each training session, which were importantly expanded during trainings by the Instructor. (See Appendices A-C for overviews of Palliative Player Training Sessions *as delivered*.) Volunteers who missed training sessions were offered make-ups with the Project Coordinator. Each Palliative Player covered the material in all three training sessions before role-playing in CHASICP workshops for CHA staff.

Because the Palliative Players are valued hospice volunteers, not actors doing part-time work, managing these volunteers to ensure their satisfaction with the project was essential. This responsibility was assigned to the Project Coordinator, in close cooperation with the Director of HVOWC.

## 1. Recruitment

Hospice volunteers were recruited in person and by email by the HVOWC Director, who offered the opportunity to train to serve as Palliative Players to help improve the communication skills of area healthcare workers by serving as SPs in role-play trainings for clinical staff at two area hospitals. Recruitment criteria included:

- Availability for role-play up to one half day a month.
- Reliability - known to fulfill commitments as a hospice volunteer.
- Communication skills - able to respond to cues from learners.
- Low emotional reactivity about the end of life and experiences with clinicians.
- Ability and willingness to support didactic agenda of workshops.
- Supportiveness of safe learning environment.
- Ability to remember complex set of guidelines without anxiety.

## 2. Palliative Players Training

Palliative Player training included three two-hour sessions. Agendas for these training sessions were provided in the Palliative Players Training Materials packet given to each Palliative Player. These materials included: three training session overviews, case information and scripts for three role-playing scenarios, a handout on emoting in role-play, a SICP conversation key element guide, and a VitalTalk element guide. (See Appendices A-L for these materials.)

All Palliative Player training sessions were cooperatively lead by the four-person training team. For a class of 12 recruit Palliative Players, a *minimum* of three trainers able to offer feedback on practice role-play was required. Five volunteers completed the training and serve as SPs in CHASICP workshops.

The three training sessions included:

#### Palliative Players Training Session One

- introductions,
- a review of project aims and applications,
- teaching communication as a clinical skill,
- introduction of the serious illness guide,
- a description of the CHASICP workshops Palliative Players will participate in,
- a role-play demonstration.

#### Palliative Players Training Session Two

- Palliative Player role/case selection and review of medical information,
- small group read-through of the CHASICP scripts,
- discussion of improvisation and demonstrating emotion,
- discussion about managing emotion after role-play,
- small group role-play practice with one-on-one training team feedback.

#### Palliative Players Training Session Three

- a review of CHASICP workshop aims and competencies,
- making role-play opportunities to manage patient emotion,
- role-play using a Player, with training team feedback,
- small group practice role-play with one-on-one training team feedback.

### **3. Palliative Players' Personae**

The SICP materials include three simple cases for role-play, providing relevant medical case information and a very simple description of the character's age, work, relationship, and attitude (See Appendices D-F.) Each Palliative Player familiarized her/himself with all three cases, and was prepared to role-play any of these cases at CHASICP workshops, improvising from the SICP script for each case (see Appendices G-I).

The Instructor and the Project Coordinator coached the Palliative Players, individually and as a group, on adjusting emotional intensity in role-play to challenge but not overwhelm learners, especially the first time through.

### **4. Effective Palliative Player Participation in Workshops**

The individuals who volunteered to become Palliative Players were a dynamic and exceptional group, including experienced nurses, social workers, people with other relevant experience, and hospice volunteers who were also experienced actors. These volunteers were extremely enthusiastic about teaching communication skills to healthcare workers in their community. Harnessing this enthusiasm to serve the training team's CHASICP workshop goals required persistence, attention and sensitivity.

Some volunteers had personal agendas that did not align with the Instructor's teaching goals. The Project Coordinator worked individually with those volunteers to clarify the place of Palliative Players as a learning resource, not as instructors. The Conversation Key Element Guide (see Appendix K) was invaluable in helping the volunteers to develop a clear understanding of CHASICP workshop learning goals. Some volunteers were invited to participate in role-play in separate HVOWC projects featuring role-play in community outreach events, rather than in CHASICP workshops for CHA staff.

Half of the HVOWC volunteers who chose to attend trainings now serve as Palliative Players in CHASICP workshops at CHA. The Palliative Players who role-play in CHASICP workshops engage in sensitive discussions of illness, respond to the learners with emotion, and allow intensity to build and subside naturally in response to each learner's conversational skill.

## **5. Ongoing Feedback from Palliative Players**

Debrief and coaching conversations between the Project Coordinator and individual Palliative Players are held as needed following workshops. These conversations are a valuable source of improvement input.

## **6. Opportunity for Additional Role-Play with Palliative Players**

Conversation Support Luncheons are being offered at CHA to provide staff who have completed a CHASICP workshop opportunities for additional instructor-supervised role-play practice with the Palliative Players, using the SICP Guide and VitalTalk tools.



## Findings

1. As anticipated, not all Palliative Player training participants completed the training, and not all Palliative Players were suited to service in these CHASICP workshops.
2. Five volunteers successfully completed the training and serve as SPs in CHASICP workshops.
3. The Conversation Key Element Guide (see Appendix K) was invaluable in helping the volunteers to develop a clear understanding of CHASICP workshop learning goals.

## Conclusions

The responses of real patients to the delivery of bad medical news and the broaching of goals of care questions do not usually conform to the simple script the SICIP Guide provides. Additional communication tools, and practice managing patients' strong emotion, can improve patient and provider experience (Michalakes, 2017).

SICIP and VitalTalk teach the delivery of prognosis and subsequent discussion of goals of care in a single, concise conversation. VitalTalk and the SICIP materials are designed for physicians, osteopaths, and nurse practitioners, and stress the importance of clear delivery of prognostic information to the extent that the patient wishes to be given this information. It is not always possible in a single conversation to deliver prognosis, allow patients to adjust to bad medical news, and discuss goals of care (Michalakes, 2017).

Some CHA nursing staff, chaplains, and social workers participating in these CHASICP workshops did not believe the delivery of bad medical news, a crucial component in SICIP Guide based conversation, to be within their scope of practice (Campbell, 2017; Dwelley, 2017; Mattson, 2017; Snow, 2017). Using the SICIP Guide to teach communication skills to these healthcare workers required adaptation of the scripted language and cases for use in support conversations. CHA nursing staff, chaplains, and social workers reported willingness to discuss functional prognosis with patients (and in role-play).

## Dissemination

The plans and materials attached in the Appendices below were developed for use by HVOWC and Dr. Michalakes. They were not intended for broader dissemination, though they may serve as a reference point for others seeking to undertake similar projects.

This capstone project will be made available through the Digital Commons of the University of Southern Maine.

## Other Opportunities

HVOWC is expanding the Palliative Players project as the core of a community outreach and education campaign. Other programming featuring Palliative Players is currently under development, including:

- End Stage - improvisational theater using audience-provided scenarios to explore EOL topics,
- Dying Better by Talking Sooner - advance care planning workshops, and programming for clergy and faith communities.

Future projects featuring role-play by Palliative Players may include:

- Doc Talk - how to raise end of life issues with doctors,
- Expressing Empathy - mini-workshops teaching communication techniques and tools for healthcare workers.

# Appendices

## A. First Palliative Player Training Session Overview

The first Palliative Player training session will include:

1. Introductions around the room - including
  1. Short comments on personal experiences with communication about serious illness with healthcare workers.
  2. Review of the Palliative Players project aims and applications.
  3. Review of the Palliative Players training plan tonight and overall
2. Teaching communication as a clinical skill
  1. Broken into steps.
  2. Checklists/mnemonics.
  3. Role-play
3. Introduction of SICP guide – format, roles, key elements.
4. Description of trainings for healthcare workers
  1. Training plan and format.
    - Structuring conversations.
    - Key elements of conversations.
  2. Lay out use of Palliative Players.
    - Players' responsibilities as interactive tools
      1. Specific roles.
      2. Showing emotion.
      3. Responding to key elements.
    - Instructor responsibilities
      1. Coaching.
      2. Time-outs.
      3. Re-wind.
5. Demonstration role-play by leaders
  1. Set up as for healthcare worker trainings – two chairs
6. Questions & answers, debrief.
7. Cases for Palliative Player review at home.
8. Player feedback collection.

## B. Second Palliative Player Training Session Overview

The second Palliative Player training session will include:

- Introductions.
- Palliative Player role selection
  - Experience, emotion, and demographic fit.
  - Medical case information review and description.
    - Include opportunity for questions.
- Read through of scripts in pairs/small groups.
  - Each Player to read patient part in their selected role.
- Discussion of improvisation skills and demonstrating emotion.
  - Inhabiting your character.
  - Tones of emotion
    - Bringing your personal emotional experience.
  - Leaving yourself out of the conversation.
  - Going into neutral during time-outs.
- Manifesting emotion during role-play
  - Verbal communication.
  - Physical communication.
  - Silence.
  - Turning up the emotional volume.
- Managing emotion after role-play.
  - Releasing the trauma.
    - Returning to yourself.
    - Affirming your health and well-being.
- Questions & answers (especially medical/character questions), debrief.
- Role development handouts.
- Role-play target elements materials.
- Player feedback collection.

## C. Third Palliative Player Training Session Overview

The third Palliative Player training session will include:

- Introductions.
- Review of Instructor's aims in teaching sessions for healthcare workers.
- Outline of key elements healthcare workers will practice in role-play.
- Review of role of Palliative Players.
  - Learning to climb a tree.
  - Matching the healthcare worker's skill level.
  - Responding positively to key elements.
- Role-play demonstration using volunteer from group, with Instructor feedback.
- Discussion of modulating emotion.
  - Turning up the heat.
- Small group practice with feedback.
- Questions & answers, debrief.
- Palliative Player feedback collection.

## D. Elderly Parkinson's Patient Case Information

- 84-year-old retired high-school teacher
- Parkinson's disease; medications no longer working as well
- Two hospitalizations this year; one with an ICU stay due to complications from hip surgery after a fall
- Worsening balance issues and several falls at home; decreased appetite
- Spouse deceased
- Lives below his daughter in a two-story multifamily home
- Two kids live locally; multiple grandchildren
- **Setting:** Primary care clinic; you know the patient very well

S/he is a candidate for a discussion using the Serious Illness Conversation Guide to understand more about his/her values, goals, and the type of care he/she would want as the illness progresses.

### **As the healthcare worker prepares to meet with Mr./Mrs. Brown, they consider the following:**

- Mr./Mrs. B has Parkinson's disease, multiple falls and hospitalizations
- **Prognosis:** Given the recent hospitalizations and declining functional status, there is concern that the patient is at risk for repeated hospitalizations and increasing difficulty managing at home on his/her own.
- He/she would therefore benefit from a discussion about his/her goals and priorities for future care.

Adapted from materials accessed at: [https://www.ariadnelabs.org/wp-content/uploads/sites/2/2017/05/SI-CG-2017-04-21\\_FINAL.pdf](https://www.ariadnelabs.org/wp-content/uploads/sites/2/2017/05/SI-CG-2017-04-21_FINAL.pdf)

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## E. COPD and CHF Patient Case Information

- 72-year-old retired barber/hairdresser
- COPD, CHF, diabetes, osteoarthritis, obese
- Just been referred for home oxygen
- Two hospitalizations this year for CHF
- Needs help with shopping
- Difficulty walking two blocks
- Married and lives with spouse; adult children do not live locally
- **Setting:** Primary care clinic or hospital
- Note: If in the hospital, patient came in for a COPD exacerbation and improved with treatment; now feeling somewhat better and able to engage in conversation

\*S/he is a candidate for a discussion using the Serious Illness Conversation Guide to understand more about his/her values, goals, and the type of care he/she would want as the illnesses progress.

**As the healthcare worker prepares to meet with Mr./Mrs. Smith, they consider the following:**

1. Mr./Mrs. B has COPD, CHF, and multiple co-morbidities
2. **Prognosis:** Given the hospitalizations and functional challenges, you estimate his/her prognosis as likely less than 2 years, but death could be sudden and without warning.

### Prognostication in Heart Failure

Fast Fact #143

<https://www.capc.org/fast-facts/143-prognostication-heart-failure/>

**Authors:** Gary M Reisfeld, MD; George R Wilson MD

Adapted from materials accessed at: [https://www.ariadnelabs.org/wp-content/uploads/sites/2/2017/05/SI-CG-2017-04-21\\_FINAL.pdf](https://www.ariadnelabs.org/wp-content/uploads/sites/2/2017/05/SI-CG-2017-04-21_FINAL.pdf)

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## F. Pancreatic Cancer Patient Case Information

- 52-year-old engineer
- Stage IV pancreatic cancer
- S/he is receiving chemotherapy; 3 months of chemotherapy so far
- Metastases shrinking on CT Scan
- Patient is here alone
- Spouse very involved; 1 adult son
- Patient returned to work 4 weeks ago
- **Setting:** Oncology or primary care office; you know the patient very well

\*S/he is a candidate for a discussion using the Serious Illness Conversation Guide to understand more about his/her values, goals, and the type of care he/she would want as the illness progresses.

**As the healthcare worker prepares to meet with Mr./Mrs. Jones, they consider the following:**

1. The patient has stage IV pancreatic cancer.
2. **Prognosis** at this stage is likely months to a year

## Chemotherapy: Response and Survival Data

Fast Fact # 99

<https://www.capc.org/fast-facts/99-chemotherapy-response-and-survival-data/>

**Authors:** Charles F Von Guten, David E Weissman MD

Adapted from materials accessed at: [https://www.ariadnelabs.org/wp-content/uploads/sites/2/2017/05/SI-CG-2017-04-21\\_FINAL.pdf](https://www.ariadnelabs.org/wp-content/uploads/sites/2/2017/05/SI-CG-2017-04-21_FINAL.pdf)

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## G. Elderly Parkinson's Patient Script

The healthcare worker's goal in this discussion is to explore wishes for future care using the Serious Illness Conversation Guide. The focus should be on values and goals for the months ahead rather than procedures and therapies.

**Palliative Player: You are amenable to this conversation**, but you are not sure what this conversation is about. When asked, you are clear about your wishes.

---

*Healthcare Worker*

*Palliative Player*

How are things going?

***Same old, same old.***

Is it ok to talk about how things are going with your health?

***OK, but you and I have known each other a while. You know me, my kids know me. What is there to talk about?***

What is your understanding now of where you are with your illness?

***I know this Parkinson's is going to be the end of me, but I'm a fighter. I've lived through worse.***

How much information about what is likely to be ahead with your illness would you like from me?

***Keep it to the big picture. How much time I've got left is up to God.***

Adapted from materials accessed at: [https://www.ariadnelabs.org/wp-content/uploads/sites/2/2017/05/SI-CG-2017-04-21\\_FINAL.pdf](https://www.ariadnelabs.org/wp-content/uploads/sites/2/2017/05/SI-CG-2017-04-21_FINAL.pdf)

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*Healthcare Worker*

Share prognosis as a range, tailored to information preferences.

***Or share functional prognosis:***

I hope that this is not the case, but I'm worried that this may be as strong as you will feel, and things are likely to get more difficult.

If your health situation worsens, what are your most important goals?

What are your biggest fears and worries about the future with your health?

What abilities are so critical to your life that you can't imagine living without them?

*Palliative Player*

**That's not a surprise to me, but there's nothing we can do about it.**

***I want to stay in the house I've been in for 40 years. I want my independence. It would be great to see my oldest grandkid go to college. He/she is 15 and reminds me of my spouse.***

***I've been through a lot. My faith always gets me through.***

***I want to be able to take care of myself, use the bathroom on my own. I want to feel like myself and do the things I like to do. I want my dignity.***

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If you become sicker, how much are you willing to go through for the possibility of gaining more time?

***I don't want any of those things. No tubes or machines. I saw my wife die in the hospital and I don't want that.***

How much does your family know about your priorities and wishes?

***I don't want to add to my kids' worries. They have their own lives.***

*\*Question approximates learner script*

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## H. COPD and CHF Patient Script

The healthcare worker's goal in this discussion is to explore wishes for future care using the Serious Illness Conversation Guide. The focus should be on values and goals for the months ahead rather than procedures and treatments.

**Palliative Player: You are emotional.** You are scared that things are getting harder than they used to be, like running errands. You are sad and emotional when you hear your prognosis.

---

*Healthcare Worker*

*Palliative Player*

How are things going?

***I'm getting by.***

Is it ok to talk about how things are going with your health?

***Whatever you want. I'm easy***

What is your understanding now of where you are with your illness?

***I don't feel like I used to. Some things are harder than they used to be. My husband has to run errands with me now.***

How much information about what is likely to be ahead with your illness would you like from me?

***I want to know everything.***

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*Healthcare Worker*

Shares prognosis as a range, tailored to information preferences

***Or share functional prognosis:***

I hope that this is not the case, but I'm worried that this may be as strong as you will feel, and things are likely to get more difficult.

If your health situation worsens, what are your most important goals?

What are your biggest fears and worries about the future with your health?

What are your strengths that help you manage your health? \*

*Palliative Player*

***Is that really true?***

[Be sad. Turn away from the clinician and put your head down and hands over your eyes. Re-engage in 15-30 seconds after the clinician allows silence.]

***I've been feeling weaker but that news is a lot to take in. I know this is important though. I've been worried about this for a while.***

***I want to be able to play cards with our friends. I want to spend more time with my family.***

***I worry about suffocating. That happened before I went into the hospital and it was terrifying. I hate feeling more dependent on my spouse and friends.***

***My family and my friends give me strength. They help me get through.***

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*Healthcare Worker*

What abilities are so critical to your life that you can't imagine living without them?

If you become sicker, how much are you willing to go through for the possibility of gaining more time?

How much does your family know about your priorities and wishes?

*Palliative Player*

***Being able to interact with my partner is the most important thing. I'm not running marathons or anything.***

***If going to the hospital means I can feel better when I get short of breath and have more time with my family, I want that. If there comes a time when I'm just a vegetable, I wouldn't want to put my spouse through that.***

***I signed the proxy form already; it is my partner. I don't want to worry the kids about all of this. They're living their lives.***

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## I. Pancreatic Cancer Patient Script

The healthcare worker's goal in this discussion is to explore wishes for future care using the Serious Illness Conversation Guide. The focus should be on values and goals for the months ahead, rather than procedures and treatments.

**Palliative Player: You show resistance.** You are not sure you want to engage in the conversation, but you proceed once the clinician reassures you. When you get your prognosis, you are not ready to believe that time is short because you will beat this.

---

*Healthcare Worker*

*Palliative Player*

How are things going?

***Things are ok, feeling better in the last few weeks. I went back to work last week.***

Is it ok to talk about how things are going with your health?

***I'm really feeling ok right now. Do we have to talk about this?***

Once the clinician explains the goal of the conversation, you say –

***Ok, I understand. Let's talk.***

What is your understanding now of where you are with your illness?

***I know I have pancreatic cancer and that it spread, so I know it's not good, but I've been feeling a bit better recently.***

How much information about what is likely to be ahead with your illness would you like from me?

***I want to know everything I can about what's going on.***

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*Healthcare Worker*

Share prognosis as a range, tailored to information preferences

***Or share functional prognosis:***

I hope that this is not the case, but I'm worried that this may be as strong as you will feel, and things are likely to get more difficult.

If your health situation worsens, what are your most important goals?

What are your biggest fears and worries about the future with your health?

*Palliative Player*

***I'm not like everyone else. I'm going to beat this. I deal with this by staying positive. Are you really saying I only have that long left to live?***

[Give resistance for 15 seconds. When the clinician aligns with your hopes but explains the need to plan for the future, proceed with the conversation.]

***My son's wife is pregnant; I want to see my grandchild. I was planning to retire in 1 or 2 years and my spouse and I want to travel. In the meantime, I want to spend as much time as I can with my family.***

***Being a burden. Having my partner see me really sick. Being helpless. Leaving my partner alone without things being in order. I worry about what happens if the treatment stops working.***

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*Healthcare Worker*

What are your strengths that help you manage your health?

What abilities are so critical to your life that you can't imagine living without them?

If you become sicker, how much are you willing to go through for the possibility of gaining more time?

How much does your family know about your priorities and wishes?

*Palliative Player*

***Supporting my family and knowing I can be there for them.***

***I want to be able to spend time with my family. We love talking over dinner together. I want to be able to think clearly. I don't want to spend any time in a nursing home. My father had a terrible experience in a nursing home.***

***I want to do whatever I can to have time to spend with my family so I can see my grandkid and spend time with my partner, now that we'll have more time after I retire.***

***I haven't talked with my partner about my wishes, but now I'm wondering if I should. My son and his wife are so busy I don't want to bother them.***

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## J. Emoting in Palliative Player Role-Play

Imagine yourself receiving bad medical news....

- Think about how you would react:
  - Fear
  - Anxiety
  - Shock
  - Stunned-ness
  - Confusion
  - Guilt
  - Sadness
  - Indecision
  - Assertiveness
  - Frustration
  - Anger

When you are shocked, how do you react? How does it show?

When you are scared, how do you react? How does it show?

Please think about how **you** express emotion.

- How does your body show emotion?
- How does your tone express emotion?
- How can you be comfortable expressing and showing emotion in our role-playing?

You should probably choose to go with a reaction that you will feel comfortable with displaying – and, if you can, *feeling* – in public.

Sometimes actors get so connected to their role that they cry, even keep crying once they are in a time out.

***Please remember to take a few moments to let go of the emotion of a serious illness conversation role-play and come back to being your usual, healthy self. Make sure you don't carry the shock and grief home ~***

## K. Conversation Key Element Guide for Palliative Players

(In Serious Illness Conversation Guide Role-Play)

In role-plays based on your scripts, the key elements the learner should include in your conversation are:

1. Setting up the conversation
  - Introducing this conversation and its benefits
  - Asking permission to proceed with this conversation
2. Assessing your understanding of your illness and how much information you want (and other information preferences if any)
3. Sharing your prognosis
  - Tailoring information to your preferences
  - Allowing silence
  - Exploring your emotion
4. Exploring key topics
  - Your goals
  - Your fears and worries
  - Your sources of strength
  - Critical abilities you want to defend
  - Tradeoffs you would consider
  - Family informed-ness
5. Closing the conversation
  - Summarizing the conversation and prognosis
  - Making a recommendation for how to proceed
  - Affirming commitment to the relationship with the patient

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## L. VitalTalk Key Element Guide for Palliative Players

If you notice a healthcare worker using the skills below in role-play with you, reward this by responding positively if/as your character and the role-play allows.

- “R E M A P”
  - Reframe the situation
  - Expect emotion
  - Map out what is next
  - Align with patient’s goals
  - Plan for future care (agreement on a plan)
  
- “N U R S E”
  - Name the patient’s emotion
  - Understand what the patient is thinking (check by restating)
  - Respect the patient’s effort, love, care
  - Support – convey that you are in this with the patient
  - Explore in more detail what the patient means/is thinking about
  
- Ask – Tell – Ask
  
- Delivering the headline – not the clinical details
  
- Allowing silence – up to 20 seconds
  
- Saying “I hope.... And I worry....”

Source: Materials distributed by Arnold, Back, & Tulsky at: Addressing Goals of Care - VitalTalk: Intensive Small Group Training. American Academy for Hospice and Palliative Medicine: Annual Assembly, Phoenix, AZ. February 22, 2017.

## M. Palliative Player Training Feedback Sheet

⇒ Please take a minute to help us do this better!

Did you have fun tonight?

What part(s) of this training worked well for you?

What part(s) of the training could we improve? How?

What do you wish we had done more of?

Anything you would skip or add?

How was the timing? Too long or short?

Do you feel prepared enough to role-play with learners?

Was feedback from Dr. Michalakes easy to understand? Helpful?

Could we make learning your case easier for you? How?

Do you have any questions? (Ask them here, and we will share the answers with the group if it is appropriate.)

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